



CCKO Functions of a Complex Care Clinic and Program Standard

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Introduction

An abundance of clinical and medical subspecialty expertise exists throughout the various tertiary care facilities across the province; however, access to such expertise presents a challenge for many Children with Medical Complexity (CMC) and their families. Prior to the Provincial Council for Maternal and Child Health's Complex Care for Kids Ontario (CCKO) Strategy, a number of Complex Care Ambulatory Clinics¹ had emerged in the province, demonstrating the ability to better service CMC through new models of care, and to create greater linkages between tertiary and community care settings.

The value added by a Complex Care Team model of care is not merely found in the clinical expertise that these teams provide, but is rooted in the philosophy and approach to care.

The CCKO "Functions of a Complex Care Clinic and Program Standard" has been developed to detail the mechanisms that operationalize the values of the complex care approach. It also provides standards for program level activities for developing and evolving programs.

Key Assumptions: Families are actively engaged in the care of the CMC. The health of these children is dynamic, and there is potential to change from low to high users of acute care and vice versa, at different points in time.

Model

- ✓ CCKO Complex Care Ambulatory Clinics provide team-based care in partnership with the child/youth and family. In the best circumstances, the community service and specialist provider partners attend scheduled clinic visits.
- ✓ The clinic is ideally nurse practitioner (NP) led and delivers inter/multi/transdisciplinary, integrated collaborative care and care coordination by a Key Clinical Worker, who is the primary point of contact for the child/youth and family
- ✓ Every child/youth and family has a primary care physician (PCP) within the CCKO Complex Care team
- ✓ The NP works to full scope of practice, with knowledge of the medical and social circumstances of the family
- ✓ The NP role is a clinical and leadership function for the coordination of care within the complex care team
- ✓ The NP leads the coordination of integrated care with other specialities within the hospital and with other organizations and sectors; this is a relationship based process facilitated by a shared commitment held across all involved with the clinical and service requirements of the child/youth and family.
- ✓ The NP oversees the scheduling of ambulatory care to minimise the number of visits to the hospital
- ✓ The NP is supported in coordination work by non-clinical staff
- ✓ The NP leads (facilitates and coordinates) the development and management of the care plan with the family, other team members and specialists

¹ Complex Care Ambulatory Clinics first developed where the need was identified as an evolution of inpatient paediatric complex care programs, to provide the level of care required for these children / youth and their families.

Objectives of a Complex Care Clinic

1. Integrated Care
2. Care Coordination
3. Communication and Information Sharing
4. Proactive Care vs. (only) Reactive Care
5. Advocate, Mentor, and Support for Child/Youth and Family Strengths
6. Establishing Clear Goals of Care *with* the Family
7. Caring for the *Whole* Family

1. Integrated Care

Integrated care is described as a contrast to “fragmented, episodic care”:

- a) *“Integrated Patient Care is care that is coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients’ needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health.”ⁱ*
- b) A user-led definition (that) supports a defining narrative and purpose for integrated care strategies at all levels of the systemⁱⁱ: *“My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes”ⁱⁱⁱ*

2. Care Coordination

Care coordination is a relationship-based endeavour. The CCKO Model for Complex Care involves care coordination which is ideally led by an NP acting as the **Key Clinical Worker (KCW)** for the child/youth and family. The KCW is the primary point of contact for the child/youth and family, and will engage other members of the care team as necessary to ensure that the care being delivered is as planned after an assessment of the needs and strengths of the child/youth and family, the shared understanding of which drives planning to meet the family goals of care.

In active partnership with the child/youth and family, as well as with other providers and programs within and across organizations and settings, the goals of care are achieved while scheduling and structuring appointments to reduce the burden of travel for the family, minimizing the number of times a child/youth and family must re-tell their ‘story’, and eliminating ‘siloes’ issue- or condition-specific assessments, information and treatment.

The **Key Clinical Worker (KCW)** and other members of the team work to build relationships and strategic partnerships within their organizations and with community partners. This involves bringing subspecialists and relevant community partners into the clinic as indicated, with the child/youth and family’s permission. The KCW ensures that the most up to date clinical/care information document/care plan is accessible and available to the circle of care in as timely a way as is feasible,

using information and communication technologies, to ensure that the teams make appropriate and timely decisions for ongoing care of the child/youth and family.

Actions (include, but are not limited to):

- ✓ With the child/youth and family, assess the needs and strengths to guide the focus and develop the plan of care.
- ✓ Coordinating the collaboration of the multidisciplinary team, with other specialists/clinicians within the organization, other organizations and settings² through:
- ✓ Bringing different disciplines to the complex care visit instead of having the child/youth and family have to go from one appointment to another repeating their 'story' (e.g., the social worker and dietician participate in the clinic visit to understand the child/youth and family strengths and needs, as opposed to having the child/youth and family sent after the NP and/or MD appointment to see the Social Worker or Dietician in a separate appointment).
- ✓ Scheduling appointments (including investigations, procedures, hospitalizations, surgeries, multi-inter disciplinary meetings) to meet the child/youth and family's preferences (wherever possible)
- ✓ Where possible, have other physician specialists (e.g., respirologist, gastroenterologist, neurologist, etc.) see the patient with the complex care team or perhaps consult to the complex care team to save the child/youth and family a visit to another specialist (if this is the preference of the child/youth and family)
- ✓ Holding **Family-Focused Team Meetings/Case Conferences** with the interdisciplinary team (complex care core team, LHIN CC, allied health, pharmacist, other medical specialists and the child/youth and family present, when "big or challenging issues" arise (medical issues or other crises, this includes transitions).
- ✓ Involving LHIN Care Coordinators (previously CCAC) in clinic visits³
- ✓ Collaborating with Children's Treatment Centre (CTCs)/Children's Treatment Networks (CTNs) (see footnote regarding LHIN Care Coordinators)
- ✓ Engaging or support the engagement of members of the child's school by LHIN CCs
 - ✓ Identifying *with* the child/youth and family which other community members are important to engage
 - ✓ Where a family doctor or primary care Nurse Practitioner provides care to the child or youth, actively partner to keep that relationship intact; ensure updates of information include these primary care providers. This will also facilitate transition if the child or youth stabilizes so as to no longer require complex care, or when they transition out of the paediatric system to adult health services.

The Complex Care intake appointment marks the beginning of an ongoing, comprehensive assessment with the child/youth and family, which informs the team's understanding of the child/youth and family's context. Subsequent meetings and appointments are arranged with specialists in attendance as needed,

² As much as community providers are willing and able to participate.

³ The ideal is that a community service provider attends scheduled clinic and it is a program function to continue to advocate for this partnership. At this time it is the ideal yet is outside of the Provincial Council for Maternal and Child Health's authority to make the attendance of a community care partner a required standard.

whether in person or facilitated using communication technologies. The KCW may need to maintain frequent communication with specialists, as indicated, to bring all members together and ensure that all aspects of care are addressed within a shared context, as opposed to addressing them in clinical isolation.

3. Communication and Information Sharing

The KCW as the primary point of contact facilitates easy access and communication between the child/youth and family and the care team. A **Complex Care Plan** is developed *with* the child/youth and family and the input of other disciplines and specialists, and distributed to the **Most Responsible Physician (MRP)** and, with the child/youth and family's permission, to care providers within the **circle of care** to support information sharing. The care plan is developed, used and updated in accordance with the CCKO Care Plan Standard. The KCW ensures that the Complex Care Plan, along with all relevant consult notes, letters and other visit summaries are sent to the **Primary Care Provider (PCP)** in the community, and other providers within the circle of care. Patient privacy and permission is always considered in distributing materials containing personal health information (PHI) and other confidential materials in accordance with relevant legislation.

Actions (include, but are not limited to):

- ✓ The Complex Care Plan is a required and major communication vehicle that is supportive of collaboration and information sharing (see CCKO Medical Care Plan Standard for details).
- ✓ Communicate in-person through face-to-face meetings, as appropriate, and,
- ✓ Where appropriate, make use of communication technologies, which may include the telephone, email messages, text messages, and Ontario Telemedicine Network (OTN) video-conferencing.

4. Proactive Care vs. (only) Reactive Care

Reactive care refers to dealing with the immediate crises or symptoms: the “presenting problem.” While a reactive approach *is* necessary in providing care, it is not the only approach which should be considered. Proactive care refers to the process of taking an active role in identifying a potential problem or concern, and determining activities that will reduce the incidence or severity of the potential problem. Proactive care covers things like routine screening practices, and early intervention to prevent disease (e.g., bone screening every six (6) months and possibly prescribing medicines to optimize bone health). Frequent communication with the primary care provider and other members in the circle of care, for role clarification and information sharing, is a necessary approach to delivering proactive care, as these practices encourage ongoing collaboration and proactive identification of potential areas where additional support might be beneficial for the child/youth and family.

Actions (include, but are not limited to):

- ✓ Monitoring and ensuring that the child/youth's baseline care needs are addressed
- ✓ Vaccination review, as this population is typically behind in routine vaccinations and should also receive vaccines provided to at-risk populations

- ✓ Developmental screening (e.g., hearing, vision, cognitive, etc.) and the appropriate level of early intervention thereafter
- ✓ Proactive discussions for troubleshooting (i.e., if “this” happens, do “this”)
- ✓ KCW available to the child/youth and family as a “point person” who can be contacted with questions or concerns about the child/youth’s health during business hours (the KCW may be able to suggest a measure/intervention to aid child/youth and family in managing the concern at home)
- ✓ Supporting parents/guardians and caregivers to address their mental health concerns, and advocating for appropriate services (e.g., nursing hours, respite hours, etc.) to lighten the child/youth and family’s burden
- ✓ Early introduction of a palliative care service for assistance with chronic care management
- ✓ Regularly engaging the family in discussions to inform the team’s understanding of their goals of care

5. Advocate, Mentor, and Support for Child/Youth and Family Strengths

There is an advocacy, support and mentorship role for the KCW and other members of the complex care team to empower children/youth and family members, and support the family’s development of resilience through planning actions with the child/youth and family that use their strengths. There are fluctuations in the level of support that a child/youth and family may require at any given time, depending on their level of coping, adjustment, and the crises in their current situation. The KCW, “has the child/youth and family s back,” and “walks the line” between empowering and supporting without creating dependence, stepping in at times when the child/youth and family needs additional support. The role of the KCW has developed over time to promote building capacity *within* the child/youth and family, and teams are identifying that some children/youth and families are not relying on contact with the team as frequently as the partnership evolves and capacity increases. Social workers and dieticians dedicated to the complex care team develop expertise in providing supports to the children/youth and families, thereby increasing expertise and efficiency within the team and offering specific mentorship to community partners.

Actions (include, but are not limited to):

- ✓ Teaching the child/youth and family how to recognize the early signs of a situation requiring acute care and the next steps of management, including recognizing when a situation can be appropriately managed at home, understanding when to contact the child’s PCP, and knowing when it is most appropriate to seek emergency services
- ✓ Having the KCW available to the child/youth and family to discuss any concerns or questions that the child/youth and family may have, and to assist the child/youth and family in troubleshooting, which may involve consulting other team members on their behalf to solve a particular issue.
- ✓ Early introduction of the social worker, in a (somewhat) calmer environment, to begin considerations for funding resources and additional child/youth and family support

proactively, so that when crises do arise, the foundation for that relationship has already been established

- Advocating on the child/youth and family's behalf, and contextualizing why the child/youth and family *does* meet the criteria to access a particular service or funding support
- Recommending and helping the family secure respite services in addition to home care when the family is present
- Advocating for services that *do not* exist, and supporting the child/youth and family in finding an 'innovative solution.'

6. Establishing Clear Goals of Care *with* the Family

The Complex Care intake appointment marks the *beginning* of a comprehensive, ongoing assessment *with* the child/youth and family, which will inform the team's understanding of the child/youth and family's **goals of care**. The goals can encompass things such as improving home life, going to school, or going to camp. These goals can also be specific to healthcare. For example, the child/youth and family may have a goal of attending fewer clinic appointments, and if the Complex Care team identifies that the child requires a renal ultrasound, which would usually require them to be seen by a nephrologist, the Complex Care physician might make this referral for an ultrasound directly, to assist the child/youth and family in achieving the goal of fewer appointments.

Actions (include, but are not limited to):

- ✓ Regularly revisiting the discussion of goals of care *with* the child/youth and family
- ✓ Debrief from the previous encounter to ensure that the child/youth and family's concerns are being heard and validated; this helps the child/youth and family to feel supported in what they are doing
- ✓ Facilitate conversation regarding the direction of care, treatment options including non-standard and possibly non-conventional options, advance directives, pain management, and quality of life considerations
- ✓ Considering the child/youth and family's unique dynamics and circumstances (e.g., employment, childcare arrangements, etc.) and the implications on their current situation

7. Caring for the *Whole* Family

Complex Care clinics take a holistic approach to care, which involves understand the child/youth and family structure and current services in place, and learning what *does* and *does not* work within the context of the child/youth and family. The strength and needs of each child/youth and family, and how these interplay, must be understood in order to develop effective medical care plans. The mental health needs of siblings, parents/guardians, caregivers, and other individuals, which the child/youth and family may identify as important within their family system need regular consideration. This often involves asking questions about how family members are coping, how the family is functioning in the community, and recognizing the family's life circumstances outside of the clinical environment.

Actions (include, but are not limited to):

- ✓ Identifying care needs and appropriate resources that will service the individual members of the family, and the family system as a whole, which may include:
 - Individual, couples and/or family therapy
 - Peer support groups (for parents/guardians, caregivers, siblings, extended family, family friends, etc.)
 - Resource counselling (connecting families to resources for which they are eligible, particularly in the community setting)

Help the family with the child becoming a youth/adult and deal with issues of: autonomy, communication understood by others, capacity, imparting independence/life skills, vocational planning, independent living, etc.

Scheduling time for empathy and connection

Complex Care Program Functions

The following program level functions create the circumstances in which the complex care clinic is able to meet its objectives.

Leadership

Required:

- Senior leadership support within the organization (an executive sponsor when first implementing and transition to some mechanism to maintain visibility with and support of the hospital senior leadership)
- Belief in the value for the family and thus the imperative for providers to develop and deliver care consistent with the CCKO complex care model
- Creation of a guiding coalition for the evolving program that includes the community service provider
- A mechanism to obtain families' input to the development and evolution of ambulatory complex care

Structure and Process

Required:

- Negotiating the clinical space that will support the team based clinic visits with technologically dependent children and youth and their family; access to the required equipment to conduct the visit
- A mechanism to identify the children and youth who meet the CCKO criteria and processes to provide equitable access to the CCKO complex care model
- A weekly/monthly schedule that is designed to accommodate:
 - Prescheduled clinic visits, both intake and follow up
 - Family focused / multidisciplinary rounds
 - Urgent visits (this does not imply that complex care clinics are to become *de facto* urgent care clinics)

- NP (KCW) protected time for:
 - Care coordination planning and oversight
 - Care plan development with the input and review by others within the circle of care
 - Being the point of care health partner for the child/youth and family who discusses concerns and issues by telephone, email and text according to the families preference
- Transition to adult health services enablers and readiness within program operations and practices
- Access to palliative care resources to support pain and advance directives, in addition to developing this knowledge within the complex care team

Recommended:

- Dedicated allied health team members as required for the population served, specifically Social Workers, Dieticians and Pharmacists, and others as required; some allied health resources may be in-kind services provided by community partners.

Education and Promotion

Within the organization:

- Presenting the program goals and case studies across the organization to encourage referrals, cooperation with the coordination of appointments with specialists, diagnostic services and ongoing support of the complex care approach across the organization.
- An intranet web presence with contact information and details about the referral criteria and referral process
- Education of all trainees

Outside of the organization:

- An internet web presence (on the organizational website) with contact information and details about the referral criteria and referral process
- Continue to meet with LHIN/H&CC division leadership until the agreement and process is in place for the LHIN CC to attend prescheduled complex care visits with the child/youth and family and clinical team⁴
- Presenting the program to all appropriate community forums (examples-community pediatrician groups, hospitals and other care organizations that refer to specialty care at the hospital where the complex care clinic resides)
- Education of skills/model/mentor and support providers

Regional Leadership

Regional complex care responsibilities include **capacity building** in community through the satellite model that includes tertiary NPs (KCWs) who work in the tertiary organization and also in the satellite clinic with the community hospital paediatricians, allied health and LHIN Care Coordinators and/or Children's

⁴ As the Special Needs Strategy's Coordinated Service Planning is implemented, the LHIN Care Coordinator is (tending to be) identified as the Coordinated Service Planner (CSP).

Treatment Centre allied health. Organizational support, academic support, and executive sponsorship are required to support the development of a Complex Care Program, in both tertiary and community sites.

There is a need to promote and support research and evaluation to ensure documentation of the outcomes and furthering of the model of care delivery for this unique population.

ⁱ Singer SJ, Burgers J, Friedberg M, Rosenthal MB, Leape L, Schneider E. Defining and measuring integrated patient care: promoting the next frontier in health care delivery. *Med Care Res Rev.* 2011;68(1):112–127

^{iv} Health Services Delivery Programme, Division of Health Systems and Public Health, Integrated care models: an overview, October 2016

ⁱⁱⁱ National Voices. A narrative for person-centred coordinated care. 2013
(<http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>).

Glossary

Term	Definition and Source
<p>Complex Care Team</p>	<p>A team of health-care professionals who specialize in the care of children with complex health needs. Complex Care Teams collaborate with Primary Care Providers to improve linkages between community and hospital care services.</p> <p>Children with complex health needs, also referred to as children with medical complexity include, but are not limited to children with:</p> <ul style="list-style-type: none"> ▪ Multiple health concerns and needs ▪ Multiple services and specialists involved in care ▪ Multiple medications ▪ Often rely on medical technology (such as feeding tubes or oxygen) in day to day living. ▪ Frequently visits to the emergency department or admission to hospital <p>The team does not focus on one specific disease, but rather on the consequences of many.</p> <p>Source: http://www.sickkids.ca/PaediatricMedicine/What-we-do/Complex-Care-Program/Index.html</p>
<p>Medical Complex Care Plan</p>	<p>PCMCH’s CCKO Strategy has developed a ‘Medical Care Plan Standard’ which is a required standard for ambulatory complex care clinics associated with the CCKO Strategy.</p> <p>A Medical Complex Care Plan is a written document that outlines the major medical issues and care needs for a specific child and is created by the health care provider in collaboration with the family.</p> <p>Source: Adams et al.: Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. BMC Pediatrics 2013 13:10.</p> <p>From the literature, and from speaking with families and health care providers, there is agreement that a medical care plan is a useful tool and improves quality of care. It is important to ensure that care plans are optimized to ensure that important content is included and that medical care plans are used effectively. The Provincial Council for Maternal and Child Health (PCMCH) developed Medical Care Plan Standards which outline the necessary components in detail, through the Complex Care for Kids Ontario (CCKO) team at PCMCH, working with the members of the Medical Care Plan Standards Work Group (see Appendix A of the Medical Care Plan Standard).</p> <p>Source: The Provincial Council for Maternal and Child Health (PCMCH) – Complex Care for Kids Ontario Standard: Medical Care Plan (May 9, 2017) – http://www.pcmch.on.ca/wp-content/uploads/2017/07/PCMCH-CCKO-Medical-Care-Plan-Standard.pdf</p>

<p>Key Clinical Worker</p>	<p>**The CCKO Model involves a Nurse Practitioner, who acts as the Key Clinical Worker for the family**</p> <p>The aim of the evolving CCKO Complex Care Model of Care includes the LHIN Care Coordinator involvement in scheduled visits, partnering as the ‘System Key Worker’.</p> <p>The 'key worker' model is a method of service delivery involving a person who works in a guide role with families. This person acts as a single point of contact for a family, helping the family to coordinate their care, not only within the healthcare system, but also across a broad range of systems (education, social services, financial resources, recreation, transportation, etc). The main concept of the key worker's role is to empower parents by providing them with support, resources and information tailored to meet their individual needs.</p> <p>This activity is accomplished by a variety of means which may include:</p> <ul style="list-style-type: none"> ▪ being available on a regular basis, and also when required by the family; ▪ helping parents understand the system(s) and, if required, helping them navigate the system(s); ▪ being present at various meetings/appointments if requested by parents; ▪ assisting with the interpretation of assessment results, or outcomes of meetings; and ▪ supporting the family's skills, and providing parents with additional skills or tools to facilitate empowerment. <p>Source: https://www.canchild.ca/en/resources/85-the-key-worker-model-of-service-delivery</p> <p>Concept of a "key worker" for the child and family - acknowledging the need for a lead who assumes responsibility for ensuring coordination, communication and follow-through with the plan of care. The key worker acts as the family's single point of contact within healthcare and across other systems (education, social services, financial resources, recreation, transportation, etc).</p> <p>A clinical key worker (CKW), who has a prominent focus on clinical work together with a family member who has the most direct knowledge and responsibility for meeting the child's health needs.</p> <p>Source: Longwoods, Integrated Complex Care Model: Lessons Learned from Inter-organizational Partnership http://www.longwoods.com/content/22580</p>
<p>Integrated Patient Care</p>	<p>Integrated Patient Care is care that is coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients’ needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health.</p>

	<p>Source: Singer SJ, Burgers J, Friedberg M, Rosenthal MB, Leape L, Schneider E. Defining and measuring integrated patient care: promoting the next frontier in health care delivery. <i>Med Care Res Rev.</i> 2011;68(1):112–127</p>
<p>Care Coordination</p>	<p>The CCKO intervention involves intensive care coordination, defined as: “deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshaling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care” (24).</p> <p>Source: Chapter 2. What is Care Coordination? June 2014. Agency for Healthcare Research and Quality, Rockville, MD. http://www.ahrq.gov/professionals/prevention-chronic-care/improve/coordination/atlas2014/chapter2.html</p> <p>Characteristics of coordinated care: Your practice provides coordinated care across all settings if it:</p> <ul style="list-style-type: none"> • Has a care plan (paper or electronic), which is developed with families and specifies who will perform tasks to coordinate care and identifies patient subpopulations that will benefit from linkages to needed services and resources • Designated a team member to oversee the functions of coordinating care for patients and families • Provides support and education materials for situations and conditions common to children and youth, particularly those with special health care needs • Provides assistance to families in connecting with needed services • Has reliable policies and procedures to communicate with other clinicians (particularly to ensure that referrals are completed and documented) • Has and maintains a list of community resources • Communicates and coordinates regularly with other sectors that influence child health and well-being such as: education, child care, and any other system/agency as warranted <p>Source: https://medicalhomes.aap.org/Pages/Coordinated-Care.aspx https://medicalhomes.aap.org/Documents/CareCoordinationFactsheet.pdf</p>
<p>Case Conferencing</p>	<p>Case conferencing is a more formal, planned, and structured event separate from regular contacts. The goal of case conferencing is to provide holistic, coordinated, and integrated services across providers, and to reduce duplication. Case conferences are usually interdisciplinary, and include one or multiple internal and external providers and, if possible and appropriate, the client and family members/close supports. Case conferences can be used to identify or clarify issues regarding a client or collateral's status, needs, and goals; to review activities including progress and barriers towards goals; to map roles and responsibilities; to resolve conflicts or strategize solutions; and to adjust current service plans. Case conferences may be face-to-face or by phone/videoconference, held at routine</p>

	<p>intervals or during significant change. Case conferences are documented in the client's record.</p> <p>Source: New York State Department of Health, https://www.health.ny.gov/diseases/aids/providers/standards/casemanagement/case_coordination_conferencing.htm</p>
<p>Primary Care Provider (PCP)</p>	<p>Primary care is the foundation of people’s healthcare: it supports people throughout their lifetime, from birth to death, providing comprehensive care that promotes health and well-being and prevents, detects, treats and manages illnesses. High-quality primary care is patient-focused, meaning that the care provided considers the person, not just the illness being treated; it connects people to other parts of the system when needed; and it provides ongoing care for chronic illnesses.[1-4] Primary care also forms the foundation of Ontario’s health system: it is usually patients’ first contact with the system and serves as a gateway to other health care providers such as specialist doctors, nurses, social workers and others.[5] Many primary care providers act as the main point of contact as patients move through the system, helping them navigate health care transitions and coordinate multiple appointments and treatments. High-quality primary care is considered key for building a strong health system [5,6]; it is associated with improved overall population health, a more equitable distribution of health in populations and lower health care costs. [2,7]</p> <p>Source: https://medlineplus.gov/ency/article/001939.htm</p>
<p>Child and Family-Centred Care</p>	<p>Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety is what patient- and family-centered care is all about. Studies and experience increasingly show that when health care administrators, providers, and patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase.</p> <p>Core Concepts:</p> <ul style="list-style-type: none"> ▪ <i>Dignity and Respect:</i> Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care. ▪ <i>Information Sharing:</i> Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making. ▪ <i>Participation:</i> Patients and families are encouraged and supported in participating in care and decision-making at the level they choose ▪ <i>Collaboration:</i> Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; in research; and in professional education, as well as in the delivery of care.

	<p>Source: ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED CARE IN HOSPITALS – How to Get Started... http://www.ipfcc.org/resources/getting_started.pdf</p> <p>SickKids For us, child and family-centred care is an approach to care and service delivery that recognizes that the child or patient is at the core of all that we do, and that the family is central in the child’s life and therefore central to our care processes. It is embedded in all SickKids processes of CARE (Clinical practice, Administration, Research, and Education) and extends beyond the hospital, into the community and health system where SickKids interacts locally, nationally, and internationally to shape and support health care service delivery.</p> <p>At SickKids, we believe that child and family-centred care is achieved through: respect, whereby patients and families receive personalized and compassionate care; communication, which promotes mutual understanding; and partnership, whereby children and families are engaged in their care in an authentic and collaborative way. We believe that this approach results in optimal health, patient safety, health equity, and a positive patient and family experience.</p> <p>Source: http://www.sickkids.ca/patient-family-resources/child-family-centred-care/index.html</p>
Circle of Care	<p>Note: See sharing of Care Plan within the CCKO Medical Care Plan Standard; child/ youth and family consent required to share the care plan.</p> <p>The term “circle of care” is not a defined term in the Personal Health Information Protection Act, 2004 (PHIPA). It is a term commonly used to describe the ability of certain health information custodians to assume an individual’s implied consent to collect, use or disclose personal health information for the purposes of providing health care, in circumstances defined in PHIPA.</p> <p><u>Circumstances When you may Assume Consent to be Implied</u></p> <p>A health information custodian may only assume an individual’s implied consent to collect, use or disclose personal health information if all of the following six (6) conditions are satisfied:</p> <ol style="list-style-type: none"> 1. The Health Information Custodian Must Fall Within A Category Of Health Information Custodians That Are Entitled To Rely On Assumed Implied Consent. <ul style="list-style-type: none"> ➤ health care practitioners ➤ long-term care homes ➤ LHIN Home & Community Care (formerly, community care access centres) ➤ hospitals, including psychiatric facilities ➤ specimen collection centres, laboratories, independent health facilities ➤ pharmacies ➤ ambulance services

	<p style="text-align: center;">➤ Ontario Agency for Health Protection and Promotion</p> <ol style="list-style-type: none"> 2. The Personal Health Information To Be Collected, Used Or Disclosed By The Health Information Custodian Must Have Been Received From The Individual, His Or Her Substitute Decision-maker Or Another Health Information Custodian. 3. The Health Information Custodian Must Have Received The Personal Health Information That Is Being Collected, Used Or Disclosed For The Purpose Of Providing Or Assisting In The Provision Of Health Care To The Individual. 4. The Purpose Of The Collection, Use Or Disclosure Of Personal Health Information By The Health Information Custodian Must Be For The Provision Of Health Care Or Assisting In The Provision Of Health Care To The Individual. 5. In The Context Of Disclosure, The Disclosure Of Personal Health Information By The Health Information Custodian Must Be To Another Health Information Custodian. 6. The Health Information Custodian That Receives The Personal Health Information Must Not Be Aware That The Individual Has Expressly Withheld Or Withdrawn His Or Her Consent To The Collection, Use Or Disclosure. <p>PHIPA permits an individual to expressly withhold or withdraw consent to the collection, use or disclosure of his or her personal health information, unless the collection, use or disclosure is permitted or required by PHIPA to be made without consent. In most circumstances, if an individual decides to withhold or withdraw consent, PHIPA requires the receiving health information custodians or their agents to be notified if the disclosing health information custodian is prevented from disclosing all of the information that is considered to be reasonably necessary for the provision of health care.</p> <p>Source: Information and Privacy Commissioner of Ontario - CIRCLE OF CARE: Sharing Personal Health Information for Health-Care Purposes – https://www.ipc.on.ca/wp-content/uploads/Resources/circle-of-care.pdf</p>
<p>Most Responsible Physician</p>	<p>The term Most Responsible Physician (MRP) generally refers to the physician who has overall responsibility for directing and coordinating the care and management of an individual patient at a specific point in time. With expanding scopes of practice of other regulated health professionals, it is possible in some circumstances that a non-physician might also be considered the most responsible practitioner. At least one court has described the role of the MRP as follows:</p> <p>... the practitioner most responsible for the in-hospital care of a particular patient. The MRP is responsible for writing and clarifying orders, and providing a plan of care, obtaining consultations as appropriate, coordinating care, as well as the discharge process. [1]</p> <p>The identity of who will act as MRP for a patient should be determined early, and based on the particular circumstances of each case. It should be clear in the patient's medical record which physician is designated as MRP. While typically the attending or admitting physician will be the MRP, this may not always be the case.</p>

	<p>Physicians should be aware of any policies in their hospital or institution that might define the expectations of the MRP. Many hospitals, for example, have policies that set out the responsibilities of the MRP for managing patient care during regular or on-call coverage. Some hospital policies may use the terms attending or admitting physician to designate these types of responsibilities. Physicians should also be familiar with similar policies at clinics and other facilities where patient care may be shared with other professionals.</p> <p>Source: Canadian Medical Protective Association – The most responsible physician: A key link in the coordination of care https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2012/the-most-responsible-physician-a-key-link-in-the-coordination-of-care</p>
<p>Goals of Care</p>	<p>There are many possible treatment choices in medical care that impact both quantity of life and quality of life. Decision-making is informed by many factors including disease extent and prognosis. However, treatment choices, particularly those decisions that are made in the context of a serious, life-threatening illness, are also influenced by an individual's values and preferences, and this is reflected in the patient's goals for medical care. Understanding an individual's goals of care allows clinicians to align the care provided with what is most important to the patient and his or her family.</p> <p>Sometimes the term "goals of care" is used in a very narrow sense, referring specifically to discussions about resuscitation preferences or "code status" among hospitalized patients. We suggest a broader definition that covers many steps in healthcare decision-making, including decisions about specific treatments, the intensity of care, and even planning for future care needs (advance care planning). While goals of care discussions most often occur in the context of a hospitalization, ideally these discussions should occur earlier in the disease trajectory.</p> <p>Goals of care discussions should not occur in a vacuum. At their best (particularly when they occur early in the disease trajectory), they are exploratory, conversational, and longitudinal. At their worst (particularly when they occur during a life-threatening crisis), they can feel pressured, uninformed, transactional, or even adversarial. Processing of complex information is best done outside of a crisis situation. Ideally, these discussions should begin at the kitchen table, continue in the clinic, and evolve with time. Conceived in this way, discussions about goals of care should not be limited to goals of end of life care (ie, focusing on death and dying), but as much about how the patient wants to live. Goals of care discussions are often framed around medical interventions, such as second-line chemotherapy, or hospitalization or whether or not to forgo cardiopulmonary resuscitation in a critical illness setting. In some cases, the patient's primary goals are not medical, but are more personal, and focused on where they want to be, and how they want to live their lives in whatever time they have remaining. When contemplating the end of one's life, most people think about things like completing tasks, mending relationships, atonement, and attending family events. Other health-related values that can guide how individuals</p>

	<p>conceptualize specific health care goals and medical decisions include self-sufficiency, life enjoyment, connectedness and legacy, balancing quality and length of life, and a desire to be engaged in care decisions [1]. Goals of care discussions must consider and engage each patient’s life story, to ensure that decisions are being made within this important personal context.</p> <p>Source: https://www.uptodate.com/contents/discussing-goals-of-care</p>
<p>Patient Navigation</p>	<p>In 1995 Dr. Harold P. Freeman first described patient navigation as a means for improving access to recommended cancer screening services, follow-up, diagnosis and treatment in medically underserved populations [1]. Patient navigation is a process by which trained individuals proactively guide patients through and around barriers in a complex cancer care system to decrease fragmentation of care and to coordinate services. [2]</p> <p>The Principles of Patient Navigation [3]</p> <ol style="list-style-type: none"> 1. Patient navigation is a patient-centric healthcare service delivery model. 2. Patient navigation serves to virtually integrate a fragmented healthcare system for the individual patient. 3. The core function of patient navigation is the elimination of barriers to timely care across all segments of the healthcare continuum. 4. Patient navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers. 5. Delivery of patient navigation services should be cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum. 6. The determination of who should navigate should be determined by the level of skills required at a given phase of navigation. 7. In a given system of care there is the need to define the point at which navigation begins and the point at which navigation ends. 8. There is a need to navigate patients across disconnected systems of care, such as primary care sites and tertiary care sites. 9. Patient Navigation systems require coordination. <p>Source: Primary Care Coalition – Patient Navigation Guidelines – http://www.primarycarecoalition.org/wp-content/uploads/2013/10/Patient-Navigation-Guidelines-7-2012.pdf</p>

Appendix 1 –Standard Development Work Group

Member	Title	Organization
KELLY FINLAYSON	RN, MV, Director	Children’s Hospital, LHSC
KEVIN HAYNES	Program Coordinator	PCMCH
ALEXANDRIA HOUSTON	Manager	Children’s Hospital, LHSC
SARAH KROETSCH	Social Worker	Children’s Hospital of Eastern Ontario
DONNA LAFORCE	Director	McMaster Children’s Hospital
AUDREY LIM	Paediatrician, Complex Care Program Medical Lead	McMaster Children’s Hospital
NATHALIE MAJOR	Paediatrician, Complex Care Program Medical Lead	Children’s Hospital of Eastern Ontario
KIM MCLEOD	Family Advisor	
KAREN MORRIS	Nurse Practitioner	Children’s Hospital of Eastern Ontario
KATHY NETTEN	Social Worker	The Hospital for Sick Children
JULIA ORKIN	Paediatrician, Complex Care Program Medical Lead	The Hospital for Sick Children
MARY ELLEN SALENIEKS	Senior Program Manager	Provincial Council for Maternal and Child Health
JOANNA SOSCIA	Nurse Practitioner / Clinical Lead	The Hospital for Sick Children